NHS BLOOD AND TRANSPLANT
ORGAN AND TISSUE DONATION AND TRANSPLANTATION
THE SEVENTEENTH MEETING OF THE NHSBT
CARDIOTHORACIC PATIENT GROUP (CTPG)
ON WEDNESDAY 25 OCTOBER 2023 FROM 10:30 TO 15:00
MINUTES

PRESENT

Robert Burns	CTAG Patient Group Co-Chair
Lorna Allen	Cystic Fibrosis Trust
Liz Armstrong	Head of Transplant Development, NHSBT
Andrea Barrett	Patient Representative (Zoom Hearts)
Hugh Brazier	Cardiomyopathy UK, DCM Patient, Freeman Hosp, LVAD
Nikola Brigden	Forgotten Lives UK
Andy Bright	Action for Pulmonary Fibrosis
Jon Comb	Freeman Heart and Lung Transplant Association
Tamsin Courtenay	Wife of Co-Chair; Retired GP and GP Federation Medical Director
Euan Darrach	Transplant Specialist Nurse, Golden Jubilee Hospital, Glasgow
Orlaith Dullaghan	Recipient Transplant Co-ordinator, Royal Papworth Hospital
John Forsythe	Senior Clinical Co-Chair, ISOU, DHSC
Brian Golding	Patient, Royal Papworth Hospital
Kathryn Green	Parent of Patient, (GOSH); Paediatrician
Chris Hannah	Heart Transplant Patient, Royal Brompton and Harefield
Margaret Harrison	CTAG Lay Member
Ged Higgins	UHSM Patient Representative; Electric Cranks Founder
Rachel Hogg	Statistics and Clinical Research, OTDT
Michael Hopkinson	Team Leader, Health Ethics Policy Team, ISOU, DHSC
Laurence Humphreys-Davies	British Society for Heart Failure representative
Ghayda Javed	Trainee Clinical Psychologist, Wythenshawe Transplant Unit
Jessica Jones	CT Patient Representative
Beverley Jones	Manchester ROA NHS Hospitals Foundation Trust
Peter Knox	Harefield Transplant Club
Monika Krupa	Nurse, Transplant Services, Royal Papworth Hospital
Rebeka Jenkins	Clinical Research Fellow, NHSBT
Clare Lauwerys	NHS Peer Leader
Alan Lees	Harefield Transplant Club member
Jan Lockett	Heart and Lung Transplant Patients, Birmingham
Zoey Malpus	Psychologist, PACT
Derek Manas	Medical Director, OTDT, NHSBT
Kirsty McGovern	Golden Jubilee Hospital, Glasgow
Sarah-Jane Mead Regan	Transplant Co-ordinator, Great Ormond Street Hospital
Elsa Perry	Recipient Co-ordinator, University Hospitals Birmingham.
Karen Rockell	Co-Director UK Organ Donation & Transplantation Research Network
Lucy Ryan	Heart Transplant Patient / Heart Transplant Families UK
Adrian Sims	Heart and Lung Patient (awaiting transplant)
Chris Stringfellow	Trustee of the Children's Heart Federation
Annette Tremlin	Heart Transplant Families UK
Rajamiyer Venkateswaran	Chair CTAG Hearts, NHSBT (Manchester)
Michelle Woods	General Manager, Somerville Heart Foundation

IN ATTENDANCE

Caroline Robinson	Advisory Group Support Officer, OTDT, NHSBT (Minutes)

1	**Welcome and Introductions**	**ACTION**
	• R Burns welcomed all to the meeting. • Apologies: received from Ayesha Ali, Shaun Clayton, Trevor Collins, Lynda Ellis, Nick Hartstone Ellis, Joanna Heath, Helen Hoskin, Fiona Kennedy,	

	Gemma Massie, Jas Parmar, Dylan Parrin, Janka Penther, Rosemary Pope, Philip Seeley, Laura Stamp, Claire Walter, Sarah Watson, Craig Wheelans • The Agenda and Minutes from this meeting will be posted on www.odt.nhs.uk. Copies of papers for the meeting are available on request from advisorygroupsupport@nhsbt.nhs.uk.	
2.	**Declarations of Interest - CTPG(20)08**	
	• There were no *Declarations of Interest in Relation to the Agenda.*	
3.	**Minutes and Action Points from Previous Meetings**	
3.1	Minutes of previous Patient Group meeting Accuracy and Action Points - **CTPG(22)20** The Minutes of the previous Patient Group meeting on 7 December 2022 were previously circulated and are accepted as a true record. Action Points from the last meeting were noted as follows: • AP1 – COVID therapies - R Burns and A Barratt agreed to contact the delivery team at NHS England (NHSE) to feedback patient challenges accessing COVID therapies in a timely manner. R Burns has contacted NHSE several times. The response has been that following delivery of a great many therapies, COVID treatment would be devolved to integrated care systems. This happened in June 2023. R Burns stated NHSE published information indicating that only 20% of patients testing positive for COVID eligible for treatment received a treatment. • AP2 – Long Term Survival Post-Transplant – *See Item 6* • AP3 - Evusheld as a Preventative Treatment – Response to NICE consultation– *See Item 13* • AP4 – Psychological Support for Transplant Patients – Audit on social work provision in transplant centres - *See Item 12*	
4.	**NHSBT – Medical Director's Report and NHSBT Updates**	
4.1.1	D Manas (Medical Director of Organ Donation and Transplantation (OTDT) at NHSBT and Transplant and HPV surgeon at Newcastle) gave the following NHSBT updates: • NHSBT appoints clinicians to manage some of its activities and the solid organ advisory groups. The Liver Advisory Group now has a new Chair and some employees have recently decided to 'retire and return' to work. • Finance – NHSBT receives funding for its activities from DHSC. There has not been an uplift for 5 years despite significant change and developments. This has resulted in a funding shortfall leading to a need to apply for pots of money for specific initiatives. An example of this is the Donation after Circulatory Death (DCD) programme which started as a research programme and which is now embedded in clinical practice. This costs about £3.5M per year and although it is increasingly successful, there is no sustainable funding to support it. Applications are therefore needed to continue the programme on an annual basis. • Clinical Leads for Utilisation (CLUs) – CLUs are appointed to ensure organs are utilised effectively and trusts can appraise the way acceptance or decline of organs they are offered. • Workforce – there are considerable workforce issues across the NHS with problems recruiting and retaining staff. Surgical colleagues particularly, are leaving the NHS attracted by higher salaries and opportunities abroad. • National Organ Retrieval Service (NORS) and SCORE – NHSBT commissions and funds NORS to retrieve organs across the UK. It has a small workforce of highly skilled surgeons, but there are workforce issues within teams. It is hoped the SCORE programme (Sustainable and Certainty in Organ Retrieval) will address this as well as providing certainty to donor families who are unclear when a retrieval team will arrive and donation can take place. SCORE will also look into moving retrievals to a night-time activity so that surgery can take place during the day when there are more surgical team members available.	

	• CUSUM (Cumulative Sum Control Chart – This monitors all abdominal and CT transplant centres for variances and systemic issues. CUSUMs are triggered by graft failure or patient death over a particular period and can be due to a patient's medical condition as well as issues within a centre. Triggers for CT CUSUMs are low with only 5 recorded in recent years, although there is currently an active CT CUSUM at one centre. *See also Item 4.3.* • Corneal donation – A serious shortage of corneas, with about 6000 patients currently waiting for a transplant, led to an Eye Summit earlier this year to find ways to improve this situation. • Improving information about donors – Currently a system called EOS collects information on donors to assess whether an organ can be utilised. A new system called TransplantPath will replace this providing an opportunity to collect echos, ECGs, photos and videos etc in one place. NHSBT continues to work on the introduction of a national histopathlogy service. • An ERAS (Enhanced Recovery After Surgery) programme is being developed to look at the body's response to surgery. • Work on PREMS (Patient Reported Experience Measures) and PROMS (Patient Reported Outcome Measures) discussed at previous CTAG and CTAG Patient Group meetings is being taken forward by a newly appointed Fellow, Rebeka Jenkins Rebeka.jenkins@nhsbt.nhs.uk • Technology – EVLP (Ex Vivo Lung Perfusion) for lung transplants, the 'mOrgan' machine and XVIVO for paediatric transplants and sustainability of the CT service are also being considered. Overall, workforce issues, developing a sustainable rota, issues with the digital infrastructure and connectivity in NHS remains priority issues.	
4.1.2	Delivery of Organ Utilisation Group recommendations *(See also Item 7)* – D Manas stated that NHSBT needs to deliver the recommendations published in the recent report and a number of appointments have been made to help with this. • Delivering the recommendations will be challenging as there is no funding attached. • A specific task will be to look at gaps where patients are missing out to ensure they are at the heart of the service and are empowered in future. Some very advanced tools are available currently and centres are encouraged to use these with their patients to enable them to understand their chances of getting a transplant. • Patients are encouraged to engage in groups involved in the development of the donation and transplantation service. Currently, this varies across centres. • A CT review, led by NHSE, is planned. It is felt that some external scrutiny would be helpful given the small nature of CT teams.	
4.2	Update from CTAG Lungs Summit (22 February 2023) and CTAG Lungs Meeting (26 July 2023) **– CTPG(23)01 / CTPG(23)02** • The Minutes of the July meeting of CTAG Lungs were circulated prior to the meeting. J Parmar (Chair, CTAG Lungs) was unable to attend the Patient Group meeting, so R Venkateswaran (Chair CTAG Hearts) gave an update. • The Lung Summit was held in February to look at why lung transplantation has not recovered to pre-COVID levels. During the pandemic, lung transplantation suffered across the world. In the UK, the programme ceased because COVID is a respiratory virus. However, a secondary issue is the small workforce involved in CT transplantation. If a heart is being transplanted, a lung transplant at the same unit cannot take place at the same time. Very often the heart takes priority. The summit produced 18 recommendations which have been circulated to CT Patient Group members and which will also be available shortly at https://www.odt.nhs.uk/transplantation/cardiothoracic/cardiothoracic-patient-group/ Work is ongoing to put these recommendations into practice and since the summit there has been an improvement in lung transplantation. It is hoped this will continue over the coming months.	

	• The Lung CLUs look at utilisation and why lung offers are being declined. Some declines are due to logistical reasons and surgical team availability, so each centre is being asked to use a 10° fridge which protects the organ for a longer period allowing a transplant to take place later without displacing daytime elective surgery. Data is being collected to analyse the success of this initiative. • Workforce - Lung transplantation is a long, arduous surgery which is potentially less attractive than cardiac surgery. The loss of surgeons can mean experienced colleagues are unavailable for crucial mentoring and supervision of younger team members as well as surgery. The SCORE project will look at all these issues. • XVIVO products which help transplant surgeons and perfusionists to increase the likelihood of transplantation have been recommended for lungs. However, currently there is no funding for this.	
4.3	Minutes of CTAG Hearts Meeting – 10 May 2023 – **CTPG(23)03** The Minutes from the CTAG Hearts meeting held in May were circulated. A recent meeting of CTAG Hearts was held on 15 October 2023 and the Minutes will be available at www.odt.nhs.uk when they have been approved. R Venkateswaran reported: • For the first time since 2011 and 2013, heart transplantation passed the 200 transplants mark. Usually, activity is around 170-80 per year so this is encouraging news. • DCD Heart transplants - 25% of activity this year is due to DCD heart transplants. While the very first heart transplants were usually DCD donations, the very fine time factors involved for retrieval of the heart and transplant meant the service changed to be mainly DBD (Donation after Brain Death) where the heart is still beating at the time of retrieval. The DCD concept was resurrected in early 2000s and the UK is now the world leader in this service. However, it requires a highly skilled workforce, and there is a high consumables cost. The service is being funded on a yearly basis, but now needs sustainable funding to continue beyond end March 2024 • Great Ormond Street Hospital (GOSH) changes – GOSH is a stand-alone service and does not have a retrieval team so paediatric organ retrievals are done by Papworth and Newcastle. The technique for retrieval for paediatric donors is different and extremely difficult. Very often GOSH must assess adult hearts for transplant and so weight becomes important. A 20 cm height rule has been in place for hearts offered to GOSH. To ensure equity and no disadvantage to adults, GOSH will join with Harefield as a donor zone. The new arrangement will be audited for 6 months to see how it is working. • Changing CUSUM trigger signal – Survival for 30 days posts-transplant was the former period for a CT CUSUM trigger. This was changed due to the availability and effectiveness of mechanical support for hearts. However, re-transplants which carry a higher risk for recipient survival were excluded in the analysis. To ensure the organ goes to the patient who will get most benefit, re-transplants are being considered for inclusion in the CUSUM trigger process. This will be discussed and agreed with Centre Directors and the topic will return for final approval at the Spring CTAG Hearts meeting.	
4.4	Update from CTAG Hearts CAV Working Group (19 June 2023) – **CTPG(23)04** This working group was formed as graft failure due to vasculopathy and the lack of uniformity of practice in UK CT units was raised as a concern by patients at the CTAG Hearts meeting in May. At the first meeting of the working group: • Most agreed on lipid targets, but there was unresolved discussion about what wider cardiovascular risks are relevant. • Standardisation of hypertension, diet, exercise and weight management targets are suggested for future discussion. This falls mostly under post-transplant follow up rather than within NHSBT. • Standardisation will rely on having high quality evidence to support it. While collecting information about practice is useful, dictating standards could be challenging.	

	• GP involvement in more management was discussed due to the small nature of CT teams in transplant centres. However, concern was expressed at the CT Patient Group about transplant centres handing over some care to GPs where access to appointments is difficult. GPs cannot always action work initiated in secondary/transplant care and do not always have the clinical expertise needed for management of immunosuppressant drugs. A second meeting of this group will probably take place after Christmas.	
5.	**Patient Chair Update**	
5.1	Patient Co-Chair Report - **CTPG(23)13 / CTPG(23)14 / CTPG(23)15 –** This report from R Burns was circulated and he highlighted two specific issues in the meeting: • NHSE have been consulted over changes in the way units receive funding for adult heart and lung transplant activity. A higher tariff was proposed for heart transplantation which could disincentivise units from doing lung transplants • The funding allocated for follow up is also perhaps lower than would be expected. **ACTION: R Burns will look into this in more detail and would respond on behalf of CT Patient Group.** • R Burns also highlighted the main areas of concern patients have raised in the last few months which are covered in more detail in **CTPG(23)15**. These include: ○ COVID 19 ○ Support from Transplant Centres ○ Post Transplant Life and Complications ○ Access to Primary Care ○ Psychology Support ○ Pre-Transplant Waits and Mortality ○ Financial Concerns and the Cost of Living • These will be reported to the CTAG meetings. Some issues are followed up in this CT Patient Group meeting. **ACTION: R Burns to follow up different post transplant follow up regimes between CF centres outside the meeting.**	**R Burns**
6.	**Activity & Outcome Data (actions from last meeting to add long term outcomes for paed hearts and adult lungs) – CTPG(23)22**	
	R Hogg, Senior Statistician at NHSBT currently responsible for CT work, gave a presentation of Cardiothoracic Activity and Outcomes which is circulated with these Minutes: • The heart waiting list has increased over the last 10 years from 246 in 2013-14 to 312 in 2022-23. However, in the last year, there have been 214 transplants which is the highest figure in 10 years. • For lungs, the waiting list was increasing from 287 in 2013-14 up to the start of the pandemic when both the waiting list and number of transplants drops. It is now increasing again up to 302 in 2022-23. Last year, 101 lung transplants were performed. This is 7% lower than the previous year and 37% down compared with pre-pandemic figures in 2019-20. This year has seen an increase in transplants. Details of all available reports can be found on www.odt.nhs.uk and patients are encouraged to use the risk communication tools on the website alongside their clinicians.	
	Patient Raised and Meeting Specific Items	
7.	**Organ Utilisation Programme Recommendations – ISOU / Dept of Health and Social Care – CTPG(23)05**	
	J Forsythe, former OTDT Medical Director and abdominal transplant surgeon at Edinburgh, introduced himself in his current role as Senior Clinical Co-Chair for the Implementation Steering Group for Organ Utilisation (ISOU) at DHSC. As the former Deputy Chair of the Organ Utilisation Group at NHSBT he has been asked to	

	oversee implementation of the 12 recommendations which were published in the Organ Utilisation report earlier this year accompanied by a written ministerial statement. • The aim of the Organ Utilisation Programme was to support and empower patients and clinical teams and to embed innovation in the transplant service overall so the gift from donors is honoured. ISOU has now been asked to take forward implementation of the 12 recommendations. • Utilisation of CT organs is an ongoing issue with variation across centres and there is good evidence this is impacting on patients. At ISOU's first meeting in April the number of organisations involved in the donation and transplant service (including NHSBT, NHSE, hospital trusts and other organisations) were identified. • The first task has been to ensure there is a lead to take forward each recommendation and which organisation will take lead responsibility. • The second task has been to set up groups and sub-groups to ensure there is good collaboration and engagement from all interested parties including patients, clinical groups and commissioners. Dr Nick Torpey, Clinical Director in Cambridge has agreed to oversee this work. • The sub-groups will include a patient engagement group to be co-chaired by Jessica Jones, to ensure patients are at the heart of the service. Jessica is a regular member of the CTAG Patient Group and can be contacted at jessicajessica@hotmail.com • There will be 3 groups on innovation to include histocompatibility and immunogenetics to enable some of the new developments ongoing currently. A group on H&I will meet shortly. Another group will look at xenotransplantation to advise the government on how to respond to scientific advances. • Mark Cubbon, Group Chief Executive of Manchester University NHS Foundation Trust will co-chair a group on trust engagement. • The first CT review for 10 years will be led by NHSE who are deciding on the scope of this currently and how resources will be applied. The timelines for this have not yet been decided. A paper summarising the work of ISOU was circulated prior to the meeting.	
8.	**Routine Bloods Working Group Final Report and Recommendations – CTPG(23)10 / CTPG(23)11 / CTPG(23)12**	
8.1	Implementation of Recommendations • This working group was set up to due to concerns around routine bloods taken as part of post-transplant monitoring. All the adult centres + Sheffield were involved alongside Newcastle and GOSH paediatric centres, alongside other interested parties, such as GP services. A patient survey was also completed. The final report and the recommendations were circulated prior to this meeting and were also presented at both CTAG Hearts and Lungs meetings. • The recommendations were taken to the CT Centre Directors' meeting to discuss what could be implemented. Centre Directors agreed to implement the recommendations which are applicable at a Centre level. • It was agreed centres should use compliant packaging and pre-paid postage for blood samples requested by post. • Individual units need to work with local teams and GPs regarding blood collection and it is important to note that GPs are not obliged to do this work for centres. • It is agreed that units should have systems in place to inform patients of positive/normal test results. However, there is not one system used by all centre and implementation of this and how results are sent to patients is down to each centre. Follow up funding post-transplant is not the responsibility of NHSBT and is included in block funding from NHSE. At present there is no national agreement on how follow up by centres should be done so any recommendations agreed need to be included in service specifications drawn up by NHSE.	

	• NHSBT can provide clinical guidance and emphasise that this is good practice. CT transplant is not yet part of the ICS work. Patient Knows Best https://patientsknowbest.com/ is a good resource which connects to the NHS app. NHS Digital (part of NHSE) has ambitions to improve IT connectivity overall. It is agreed that the recommendations should be taken to the Transplant Oversight Group (TOG) to see how they can be implemented nationally. To fund it, NHSE needs to be engaged. **ACTION: a) A 6M audit will be completed to go back to CTAG Hearts and Lungs meetings to see how well and which recommendations have been implemented.** **b) R Burns will work with Transplant Oversigh Group (TOG)**	
9.	**Research Update**	
9.1	UK Organ Donation and Transplantation Research Network – **CTPG(23)22 –** K Rockell, a liver transplant recipient, gave an overview of this new network of which she is co-director alongside Professor Lorna Marson and which was launched at BTS in Belfast last year - https://ukodtrn.org/ • The network has strong links with NHSBT and BTS and is hosted by Kidney Research UK. • The aim is for the UK to be a premier international location for high quality organ donation and transplantation research. • It has an Executive Board of 15 people from across solid organ transplantation and academia. A larger board consists of scientists, charities and representation from all the transplant units in the UK. • While in the past, studies usually involved one unit and a small group of people, the network aims to be a national collaborative involving cross unit and organ research to produce larger data sets. • Two big research applications have been submitted to the Medical Research Council and to the National Institute of Health Research (NIHR) to do some collaborative large-scale studies. • The first of these is about a recipient bar resource collaborating with kidney, lung and liver, possibly extending to heart if funding is successful. This would replicate the work of the QUOD biobank for recipient organs that are transplanted. • 120 patients or families have signed up for the network's newsletter. A patient public advisory group will consist of representation from all different organs, donor families, living donors and the charity sector or peer support groups. • The network's website has a couple of pages devoted to PPI; a lung representative is needed for the PPI group. Another page is devoted to training opportunities for those interested in research. • The network also aims to get researchers to provide plain language summaries of their work for patients and the public to understand. • There are Linked-in and Twitter accounts for the network and in future it is hoped to expand social media to include Instagram, Facebook and You Tube.	
10.	**Osteoporosis in Cardiothoracic Transplant Patients - CTPG(23)07**	
	L Ryan, a CTAG Patient group member who is now 30 years post heart transplant gave a presentation on osteoporosis in CT transplant patients (circulated for this meeting). • A survey with 207 responses (203 adults and 4 paediatric patients) revealed concerns regarding delayed diagnosis of osteoporosis and fragility fractures. • Solid organ patients are at risk due to bone disease, immobility pre- and post-transplant, steroid medication, CF, premature menopause etc. • 45% of pre-transplant patients and 42% of post-transplant patients have been diagnosed with osteoporosis or osteopenia. It is possible the fragility fracture rate is underestimated in the UK.	

	• Modifiable factors include taking Vitamin D supplements. 34% of patients were not taking Vitamin D and of these, 89% were not aware whether a Vitamin D blood check had been taken. • 32% of patients did not take calcium supplements post-transplant and of these 71% were not aware of any dietary assessment of diet or blood calcium levels. • Most patients were aware of the benefits of exercise. • Very few fracture risk assessments are carried out. The number of patients taking daily prednisolone for 3 months or more post-transplant were also checked, and the results are shown in the circulated report. The International Society of Heart and Lung Transplantation states that a DEXA scan should be repeated every year for patients on prednisolone. The report recommends: • Transplant centres need systems to check modifiable risk factors with patients. • There should be regular monitoring of fracture risks and/or DEXA scans. • Fracture risk should be managed according as per NOGG (National Osteoporosis Guidance Group) guidance. • Transplant centres should audit compliance with the recommendations. The issue of patients of how this will be monitored for those living a long way from transplant centres and whose care is split was raised. As immunosuppressant medication is prescribed by transplant centres, the responsibility for their side effects rest with them as well and local DEXA scans should be requested via the transplant centre to the GP so that they retain responsibility for the results. It was noted that this is a complex area as osteoporosis is likely to affect all patients and not just transplant patients. Each unit should already have a protocol to manage osteoporosis. R Burns stated that the 3 authors of the report would like the opportunity to present the report at BTS in Harrogate in 2024. **ACTION: R Burns to take this report to CTAG Lungs (October 2023) and CTAG Hearts (April 2024)**	
11.	**Update on Psychology Support for Patients – CTPG(23)08**	
	Z Malpus, consultant psychologist, joined the meeting. R Burns stated a patient survey, audit and needs analysis have been completed to identify the key issues patients have. The report and recommendations were presented last year and the direct correlation between availability of psychological support and whether patients felt their psychological needs were being met was highlighted. • A recommendation was made that the minimum level of psychology support should be 1 WTE psychologist per 350 patients. This work was picked up in the Organ Utilisation Group report published earlier this year. The work was also presented at the European Society for Organ Transplantation. • Work with PACT has resulted in some developments with one centre who previously had poor psychology support getting funding to improve this. Two other units have got half time person funding. But there is still a big disparity across the UK in provision of this service. At Papworth and Birmingham there is still low psychology support, but there is better provision at Glasgow and Manchester. • Recruitment and retention of workforce is an issue with many professionals being recruited and then being promoted to a different specialty within 6-12 months. • Heart and Lung transplantation services are retained services and are not being delegated to ICBs (Integrated Care Boards). NHS England remains the service commissioner and the requirement for multidisciplinary involvement in pre-transplant assessment including psychologists (and if indicated psychiatrists) is written into the service specifications. **ACTION: R Burns to write to NHSE highlighting the expectation that this is funded and implemented.**	
12.	**Social Work Audit – CTPG(23)09**	

	In the last patient group meeting, concern was expressed about the disparity of social work provision across transplant centres. The results of the subsequent audit completed was circulated for this meeting. • The only centres that provide adequate social work support are Manchester and the paediatric centre at Newcastle and GOSH. Most centres have no dedicated social work provision at all. • Social work should be part of transplant assessment and participate in the MDT (Multi-Disciplinary Team) meetings. This is not being achieved at most centres. • There is a difference between the hospital's social work team (which serves patients in a region) and one that is embedded in a transplant unit. • The social worker can see patients before their transplant assessment to discuss issues such as housing, immigration, cost of living. • At Manchester there is an 'open door' referral system, and the social worker attends the MDT meetings. This is not available across other centres so there is inequity of provision despite being included in the service specification. **ACTION: R Burns to write to NHSE re disparity of social work provision**	
13.	**COVID 19 Update – CTPG(23)16**	
13.1a	• This paper is circulated to highlight the significant challenges COVID presents to the CT population and continues to affect quality of life. Both pre- and post-transplant patients are reminded that they are eligible for a COVID booster vaccination and family members between ages 12-64 can also have the vaccine. Feedback from patients about the vaccine remains positive. • Update on Shingles Vaccination – This vaccine (Shingrix) is available to patients on the transplant list or those who are immunocompromised over the age of 50 (from 1 September). Patients who experience problems accessing this from their GPs, should refer them to the following link: Green Book on immunisation - Chapter 28a shingles (publishing.service.gov.uk). Immunocompromised patients must receive the non-live Shingles vaccine called 'Shingrix'. Post meeting, it was clarified that the Green Book states *'The need for booster doses following either 2 doses of Shingrix® or a single dose of Zostavax® has not yet been determined'.*	
13.1b	Other Preventative Treatments – **CTPG(23)17** • At the last meeting Evusheld, a potential prophylaxis treatment to reduce the risks of COVID. Following consultation, NICE did not approve Evusheld, but Astra Zeneca are developing an alternative. Called AZ3152. The CTAG Patient Group are formal consultees in the process going forward. N Brigden, from Forgotten Lives UK, who attended this CTAG Patient Group meeting is working to support patients with immune-suppressant issues. • Other NICE guidance/treatment – **CTPG(23)18 / CTPG(23)19 / CTPG(23)20 / CTPG(23)21** – The first draft of NICE guidance did not include treatment for post-transplant patients. The only recommended treatment was Paxlovid, which is generally unsuitable for patients due to immunosuppressant medication and drug interaction. The formal response of the group to the guidance is shown in the circulated paper. NICE adjusted their guidance to include sotrovimab. Thanks were expressed to NHSBT for their guidance to patients and to the British Society for Heart Failure for their support. • Local services - Other concerns are related to the way in which the delivery of COVID treatments have now been devolved to local teams. R Burns has been working with Blood Cancer UK and Kidney Care UK to put together a directory of services for where to access services in different regions. However, despite procedures and treatments being in place, there is very little knowledge of these when people ring up to find out information. Those at the meeting, reported having to travel long distances to get either treatment or vaccines.	**a) N Brigden** **b) R Burns** **c) K Rockell** **d) N Brigden** **e) R Hogg**

	ACTION: a) N Brigden nikolabrigden@icloud.com agreed to feedback any concerns or issues patients face to DHSE b) R Burns will feedback concerns to NHSE via Fiona Loud • Long Covid – Patients reported problems when reporting long COVID with transplant teams being unresponsive and unhelpful regarding referral. **ACTION: c) K Rockell agreed to take this issue forward as a potential research area. d) N Brigden agreed to take this forward as a useful area to pursue for data in coalition with other countries. e) Rachel Hogg also agreed to consider whether any long Covid prevalence data for SOT patients could be ascertained from the MELODY study.**	
14.	**Any Other Business**	
14.1	Electric Cranks Update and e-book – **CTPG(23)06 –** G Higgins, a patient who had an LVAD implant 10 years ago and who founded Electric Cranks in the last 4 years gave an update on the group's activities. Most of the group, who receive treatment at Wythenshawe Hospital, are Manchester based, with a recent recruit joining them from Newcastle. The group recently completed their 2nd coast to coast cycle ride raising £10K on their sponsored e-bikes and TV appearances include 'Countryfile' which highlighted the benefits for heart failure patients of having a more positive outlook and being physically active. For anyone who missed the Electric Cranks' appearance on 'Countryfile', it is still available on BBC I-Player on https://www.bbc.co.uk/iplayer/episode/m001nx7f/countryfile-countryside-cycling The group also took part recently in a sponsored abseil from a high rise building in Manchester. CT Patient Group members are invited to share the e-book circulated for this meeting with others via mobile phones, Whats App and other social media.  *The Electric Cranks group outside the transplant centre in Manchester with Professor Rajamiyer Venkateswaran.*	
14.2	Patients are invited to complete a survey on transplant services in Scotland by using the following link. The survey is open from 25 September 2023 to 29 December 2023 and should take about 10-15 minutes to complete. Survey on Organ Transplant Support and Aftercare | Organ Donation Scotland	
14.3	R Hogg gave details of the article to which she has contributed on antibody prevalence after 3 or more COVID-19 vaccine doses in individuals who are immunosuppressed in the UK: a cross sectional study from MELODY which was published in The Lancet in August 2023. The link to read this is https://www.thelancet.com/journals/lanrhe/article/PIIS2665-9913(23)00160-1/fulltext	
14.4	Network for Patients - A Barratt from Zoom Hearts is interested in forming a network of people who had solid organ transplants as children to share any issues that they have faced or continue to encounter. **ACTION: Any interested participants to contact R Burns who will pass on their details.**	
14.5	Thanks – R Venkateswaran thanked R Burns for his considerable hard work on behalf of patients and for invigorating the CT Patient Group. It is hoped that there will be continued collaboration on the projects discussed to make improvements in transplant patient care and support.	
14.6	Date of Next meeting – to be announced	

ACTIONS FROM THIS MEETING

AP1 **Item 5.1**	Future funding of CT Donation and Transplantation services from 2024 - R Burns will respond to NHSE on behalf of CTAG Patient Group.	Follow up at next CTPG meeting
AP2 **Item 5.1**	Future funding of CT Donation and Transplantation services from 2024 – R Burns to follow up concerns of different post-transplant follow up regimes between CF centres outside the meeting	Follow up at next CTPG meeting
AP3 **Item 8**	Routine Blood Monitoring - a) A 6M audit will be completed to go back to CTAG Hearts and Lungs meetings to see how well and which recommendations have been implemented. b) R Burns will take recommendations to TOG	Follow up at next CTPG meeting and at CTAG Heart and Lungs meetings
AP4 **Item 10**	Osteoporosis in Cardiothoracic Transplant Patients - R Burns to take this report to CTAG Lungs (October 2023) and CTAG Hearts (April 2024) and to submit the report to the BTS Conference for 2024	Follow up at next CTPG meeting
AP5 **Item 11**	Psychology Support for Transplant Patients - R Burns to write to NHSE highlighting the expectation that this this service is funded and implemented for transplant patients.	Follow up at next CTPG meeting
AP6 **Item 12**	Social Work Provision for Transplant Patients – R Burns to write to NHSE re disparity of social work provision	Follow up at next CTPG meeting
AP7 **Item 13.1b**	Local Services - a) N Brigden nikolabrigden@icloud.com agreed to feedback any concerns or issues patients face to DHSE b) R Burns will feedback concerns to NHSE via Fiona Loud	Follow up at next CTPG meeting
AP8 **Item 13.1b**	Local Services – Long COVID c) K Rockell agreed to take this issue forward as a potential research area. d) N Brigden agreed to take this forward as a useful area to pursue for data in coalition with other countries. e) Rachel Hogg also agreed to consider whether any long Covid prevalence data for SOT patients could be ascertained from the MELODY study.	Follow up at next CTPG meeting
AP9 **Item 14.1**	Network for solid organ transplant patients - Any interested participants who had transplants as children to contact R Burns who will pass on their details to A Barratt	Follow up at next CTPG meeting